Congress of the United States Washington, DC 20515

December 9, 2019

LaVarne A. Burton President and Chief Executive Officer American Kidney Fund 11921 Rockville Pike #300 Rockville, MD 20852

Dear Ms. Burton,

We are writing to express our strong concerns with American Kidney Fund's (AKF) decision to exit California without providing sufficient time or a clear pathway to alternative coverage for our constituents currently receiving support from your organization. Through AKF's Health Insurance Premium Payment (HIPP) program, the AKF is currently paying premiums for 3,700 enrollees across California. Many of your enrollees are low-income patients in vulnerable circumstances who could face catastrophic consequences with even a brief gap in care. We are concerned that withdrawing support without allowing for an alternative plan for coverage places these patients' lives at risk.

As Members of Congress representing your patients, we are deeply alarmed by AKF's decision to withdraw entirely from California on January 1, 2020. As a 501(c)(3) charitable organization, we expect that your organization is dedicated to the health of your enrollees. If supporting patients with end stage renal disease (ESRD) remains AKF's primary goal, AKF should work to help maintain the coverage in California that is core to AKF's patient assistance program.¹

As you well know, people whose kidneys are failing, otherwise known as ESRD, require dialysis treatment, which performs the functions otherwise performed by the kidneys.² Dialysis usually involves treatments multiple times a week for several hours at a time.³ Maintaining employment is difficult if not impossible, and the majority of ESRD patients are low-income. Many of these patients have multiple comorbidities, as ESRD is related to various other health concerns that cause the kidneys to deteriorate. These patients are vulnerable, which is why the federal government, and non-profits like yourself, have long fought to ensure they have access to quality, affordable health coverage.

¹ See October 15th Letter to Enrollees from LaVarne A. Burton urging AKF enrollees to call Governor Newsom's office and encouraging enrollees to on their own research options ("To prepare, you should begin now to research all health coverage options for which you could qualify and that you could afford in 2020, without AKF assistance.")

² "Dialysis | Hemodialysis | Peritoneal Dialysis." *MedlinePlus*, U.S. National Library of Medicine, 27 Dec. 2018, medlineplus.gov/dialysis.html.

³ "What Is Dialysis?" National Kidney Foundation, 2 July 2018, www.kidney.org/atoz/content/dialysisinfo.

Through HIPP, AKF pays premiums for enrollees who are eligible for coverage under a broad array of public programs, including Medicare and Medicaid, as well as through subsidized programs on the Exchange. AKF has helped patients afford commercial plans that may otherwise be unaffordable. We hope that AKF will take this opportunity to prove its commitment to the patients it has pledged to serve.

AKF has said that they have "no choice" but to leave California because of recently passed legislation, known as AB 290. The legislation imposes transparency, reporting, and reimbursement requirements to ensure that AKF's patient assistance program remains in compliance with federal law. However, California's Department of Managed Health Care determined that AB 290 "allows for the AKF to continue providing assistance in California."

With AKF still choosing to end HIPP assistance in California this January, many of its patients will be left stranded on plans they cannot afford. While options may be available to transition some HIPP recipients to other public coverage, we are concerned that a possible gap in coverage creates an uncertain future for many enrollees.

In particular, enrollees who were directed towards commercial coverage and had their premiums paid by the AKF may not be eligible for Medicare coverage until at least July, even if they enroll now. Many patients who enroll now, after AKF's notification, may not have coverage for nearly six months. For a patient with ESRD, this coverage gap could be devastating, if not deadly.

In addition, for enrollees who used AKF's program to pay for premiums for extended employer coverage, they may be left with no choice but to pay the entire cost of their coverage if they do not switch their coverage during the current open enrollment period. If an enrollee has job-based insurance, retiree coverage, or COBRA coverage when they become eligible for Medicare because of an ESRD diagnosis, they can maintain this coverage for up to 30 months. Many patients choose to do so with AKF's support. If these enrollees default on their high premium payments in the middle of this coverage period, many will not have a special enrollment period and thus will have no clear path to alternative coverage.

We understand that litigation has been filed to seek a review of AB 290 by a federal court. However, given that the litigation may not conclusively resolve the relevant issues before December 31st, we request responses to several questions immediately:

1) What efforts are you making to work with state and federal regulators to ensure that AKF HIPP enrollees in California will not experience a break in coverage or gaps in care? Will you consider supporting enrollees who choose to switch coverage to Medicare in covering the cost of care until they are eligible to utilize Medicare coverage?

https://secure.ssa.gov/apps10/poms.nsf/lnx/0600801247.

⁴ Department of Managed Health Care, Coverage Options for American Kidney Fund Grant Recipients, November 5, 2019. http://www.dmhc.ca.gov/Portals/0/Docs/DO/CoverageOptionsFactSheet&FAQs.pdf.

⁵ See Social Security Programs Operations Manual, Medicare as Secondary Payer of ESRD Benefits. "Once R-SMI is refused, enrollment can only take place during a GEP, with coverage effective the following July. This will usually mean a gap in coverage between the end of primary payments by the GHP and the beginning of SMI in the month of July. It may also result in a premium surcharge for late enrollment."

- 2) If the AKF does not prevail in the litigation pending in California and a federal court determines that the OIG opinion 97-01 does not protect steering into the commercial market, will the AKF commit to maintaining enrollment for all existing enrollees? What actions will AKF take for coverage of existing enrollees if the litigation is not resolved before December 31st?
- 3) AB 290 includes a provision that will postpone all of the substantive payment changes and disclosure requirements if a request to review the impacts for AB 290 is made by any party to the original Office of Inspector General opinion 97-01. Under this provision, AKF could immediately end the current uncertainty for enrollees and continue its operations in California by requesting an OIG review of the California law. Why is AKF not pursuing an OIG opinion on the impacts of AB 290 since that would immediately put AB 290 on hold until federal regulators address your objections to the California law?

Thank you for your prompt attention in this issue. We look forward to receiving your response, and we hope to work together to support California patients with ESRD.

Sincerely,

KATIE PORTER
Member of Congress

DIANNE FEINSTEIN United States Senator

KAMALA D. HARRIS

United States Senator

JUDY CHU

Member of Congress

ZOE LOFGREN Member of Congress

Man Lowenthal

ALAN LOWENTHAL Member of Congress

Roka_

RO KHANNA Member of Congress JIMMY GOMEZ
Member of Congress

DON'S MODELLA DORIS O. MATSUI

Member of Congress

JIMMY PANETTA Member of Congress

SUSAN A. DAVIS Member of Congress GRACE F. NAPOLITANO
Member of Congress

LINDA T. SÁNCHEZ

JULIA BROWNLEY
Member of Congress

NORMA J. TORRES

Member of Congress

Member of Congress